

CHILDREN'S EXPERIENCES OF END STAGE RENAL FAILURE, COPING WITH ITS TREATMENT AND SIDE-EFFECTS, AND PERCEIVED BENEFITS OF STARBRIGHT WORLD TECHNOLOGY

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ABSTRACT

It is important for professionals in education and related services for individuals with physical disabilities to understand the personal experience of children who grow up with chronic illness and the many life altering treatment regimes they undergo. Further, it is important to understand the psychosocial benefits of potential psycho-educational interventions for these children. In this case study, semi-structured interviews were used to assess personal experiences of three children diagnosed with end stage renal failure (ESRF) including their perceptions of treatment and side effects, coping strategies, and STARBRIGHT World technology. Children's personal experiences of ESRF, hemodialysis treatment, their coping strategies and perceived benefits of STARBRIGHT World technology are reported and implications for educators and related service providers are discussed.

Due to advances in health care, children with kidney disease are more likely than ever to survive into adulthood (Boice, 1998). Some children's kidney disease progresses to End Stage Renal Failure (ESRF). Three or four children out of every 1 million in the United States are diagnosed with ESRF each

year (Fennell, 2000). As children with ESRF survive to older ages, implications for education and related services also grow.

As children with ESRF mature, psychosocial issues typically problematic for adolescents, such as body image, may be exacerbated in these youths due to physical symptoms of the disease and an inability to participate in normal socializing activities such as regular attendance in school (Boice, 1998; La Greca, 1990). It is important for educators and related service providers to understand the personal experience of children who grow up with the chronic illness and life altering treatments. Further, it is important to assess techniques designed to help children adapt to the dramatic lifestyle changes associated with ESRF diagnosis.

Researchers predominately report elevated levels of depression and anxiety in children who experience kidney disease or other chronic illness (Boice, 1998; Carroll, Massarelli, & Otzoomer, 1983; Fennell, 2000). Chronic diseases impair socialization by interrupting daily activities or altering personal lifestyle to accommodate medical treatment (La Greca, 1990). Children with ESRF must endure multiple hours of dialysis treatment each week and are likely to experience minor and major surgeries as a result of the disease (Reynolds & Postlethwaite, 1996). Researchers describe incidence of social anxiety due to concerns about weight, height, and appearance in those who experience chronic illness and kidney disease specifically (Carroll et al, 1983; La Greca, 1990). Little research has examined ways in which these children cope with the diagnosis of ESRF.

Innovative technologies may address some of the concerns associated with ESRF diagnosis and may improve quality of life. Recent efforts to improve the quality of life for children with chronic illnesses have focused on technology through the Internet and closed intranets (Jerome & Zaylor, 2000; Wasem & Puskin, 2000). A new intranet technology called STARBRIGHT World was developed specifically for children and adolescents with serious and chronic health conditions (Greenman, 1998).

STARBRIGHT World is an intranet technology with limited access to the Internet that can be accessed by children through computers equipped with video cameras installed in pediatric hospital units across the country (Greenman, 1998). The goals of STARBRIGHT World are to provide (a) distraction and self-expression for children while hospitalized or during treatments, (b) peer and community social support to hospitalized children, and (c) healthcare information to children (STARBRIGHT World, 2001). STARBRIGHT World offers these psychosocial and information supports to children through a closed interactive intranet network that consists of five component areas: Activities, Connect, Find-a-Friend, Explore, and the

STARBRIGHT Zone (Holden, Bearison, Rode, Rosenberg, & Fishman, 1999).

The Activities component area provides specific distracters and opportunities for self-expression for kids. The use of STARBRIGHT World as a distracter for pain management in children has been established (Holden et al., 1999). This component area includes games, arts and crafts, and a collection of poems and short stories called The Wall. These sites are interactive so children can create their own art, poems or short stories using the technology and post them to share with others on the site. In addition, STARBRIGHT World holds regular competitions in which children may participate by submitting what they have created on the virtual network as a member of the STARBRIGHT World community.

STARBRIGHT World provides peer and community support to hospitalized children through component areas called Connect and Find-a-Friend. Connect offers chat options, video conferencing with other children, and medical bulletin boards that have the option of viewing and posting information. Find-a-Friend is a search engine that links children to others registered in STARBRIGHT World. Children can search in Find-a-Friend by specifying age, gender, special interests, or by diagnosis. Children receive personal email accounts and address books. This component area also provides video conferencing and instant messaging.

Through the Explore component area, STARBRIGHT World provides health information to children. Inside Explore children can learn about healthcare through bulletin boards and an extensive video selection that provides friendly animated explanations of medical procedures and other medical information. This component area also supplies access to news about entertainment, fashion, sports, and other current events or special interests through limited access to the World Wide Web.

STARBRIGHT Zone is a component area that provides access through email capabilities to the home page and creators of STARBRIGHT World. Children can ask questions or provide comments and change their own user profile in this component area. Other onscreen options include general function icons such as quit, help, and favorites. Children can access their email accounts by clicking on an envelope icon, which blinks to indicate new mail.

Psychosocial supports including peer interaction, peer support, community involvement, and activities offered through STARBRIGHT World specifically address many areas of concern for children diagnosed with ESRE. STARBRIGHT World technology also offers distraction to children who endure lengthy treatment hours and painful or uncomfortable procedures that may benefit those diagnosed with ESRE. The educational components

are helpful for children with ESRF to learn about procedures that they will encounter. It is important to assess children's perceived benefits of the technology for each of these component areas when determining the technology's potential usefulness.

The goals of this case study were two fold. First, due to the paucity of literature exploring the personal experiences of children diagnosed with ESRF, one goal was to collect and report the subjective experiences of children who use hospital-based hemodialysis as a treatment for ESRF and explore how these children may cope with the challenges they face. Children's personal experiences may shed light on important psychosocial and educational aspects of children's health care with implications for practice in education and related areas. In addition, the researchers sought to identify benefits of STARBRIGHT World technology as experienced by children. Understanding children's perceived benefits of the technology may influence further development and contribute to our understanding of technology's role in psychosocial and educational aspects of health care.

METHOD

PARTICIPANTS

After receiving hospital and university human subject review approvals, participants were recruited from the attending physicians' roster of patients on kidney dialysis at a local hospital. Potential participants were approached by a researcher during their kidney dialysis treatment and were asked to return consent forms if they wished to participate. Three of the five children approached for the case study returned consent forms. The three children were diagnosed with End Stage Renal Failure and participated in hemodialysis treatment 3 to 4 hours a day, 3 days a week, in a hospital setting.

Talisa. Talisa was an 11-year-old African American female diagnosed with ESRF at age 10 and began kidney dialysis approximately 12 months before the start of the case study. Talisa had been unable to attend public school for the previous two semesters; however, she returned partially to public school during the second week of data collection while maintaining a hemodialysis schedule 3 days a week. Talisa lived with her parents, sister, grandparents, and an aunt.

Joseph. Joseph was a 17-year-old African American male diagnosed with ESRF at age 16 who began kidney dialysis approximately 8 months before the start of this case study. Joseph attended a local public high school and par-

ticipated in band as much as possible. He also held a job at an athletic shoe store. Joseph lived with his grandmother and lived near many aunts, uncles, and cousins so that he often had interactions with these extended family members.

Barbara. Barbara was an 8-year-old Caucasian female. Barbara was diagnosed with ESRF at age 8 and began hemodialysis treatments two weeks prior to the initiation of the case study. Barbara lived with her mother and father and had no siblings. Her grandmother from her mother's side was very involved in the daily life of Barbara's family. Barbara had attended school regularly until two weeks prior to the initiation of the case study, when she began needing hemodialysis treatments so often that she could no longer attend. During the rest of the case study, Barbara had homebound schooling three days a week and attempted to attend regular school twice a week. She was not successful at attending regular school the majority of the time due to physical side effects of treatment.

STARBRIGHT WORLD HARDWARE

The researchers used two STARBRIGHT World computers designated for use in the pediatric kidney dialysis unit at a local hospital. The STARBRIGHT World computer technology consisted of a Dell computer with a monitor, keyboard, mouse and speakers, as well as a microphone headset and a camera used for video conferencing. The computer was plugged into a T-1 line that allowed for a direct connection to the private network through the use of STARBRIGHT World software.

PROCEDURE

A qualitative case study approach was used to explore how children diagnosed with ESRF view their experience of ESRF including its treatment, physical side effects, and ways of coping and how these children view STARBRIGHT World technology. A conceptual framework, summarized in the introduction section, was developed that encompassed both the aftermath of ESRF diagnosis documented in the literature and the potentially beneficial aspects of STARBRIGHT World technology for this targeted population (Miles & Huberman, 1994). Pre-set aims and objectives for exploration were formulated based on the conceptual framework and the paucity of literature on the personal experiences of children in hospital settings (Miles & Huberman, 1994).

Ethnographic methods including participant observation and semi-structured interviews were used to collect data (Preissle & LeCompte, 1984). Data collection took place at the pediatric kidney dialysis units of a local and

regional hospital before, during, and after hemodialysis treatment. All interview data were audio recorded and transcribed daily by an independent transcriptionist throughout the course of the case study.

Following an initial introduction of the participants and researchers, a series of regularly scheduled one-to-one semi-structured interviews were arranged corresponding with the participant's hemodialysis schedule. A researcher began each interview with qualitative open-ended questions designed to elicit broad and personal responses to gather information about the participant's experience of ESRF diagnosis, treatment, side effects and coping strategies: "Tell me about end stage renal failure." "What is kidney dialysis like?" "Tell me about the treatment and how it feels." "Can you make yourself feel better?" Follow-up queries included semi-structured questions and contrast questions that varied depending on individual responses. At the end of each 30 to 60 minute interview, a researcher completed a contact summary sheet to systematically record field notes, begin initial coding of collected data, and formulate future interview questions (Miles & Huberman, 1994).

After the described series of interviews and observations, the children were introduced to STARBRIGHT World during two individual sessions with a researcher. The first session entailed registration and basic orientation to the STARBRIGHT World network and hardware. In the second session, participants were prompted to explore the five component areas offered in STARBRIGHT World. A researcher was available to assist each participant, answer questions, and make sure every component area of STARBRIGHT world was visited at least once during the introduction.

After the introduction to STARBRIGHT World, participants had unlimited access to the technology at anytime they were in the dialysis unit. During this time, a researcher observed and interviewed each participant corresponding with his or her regularly scheduled treatments. Researchers employed methodological triangulation of data by collecting data through direct observation of social interactions facilitated by STARBRIGHT World, direct observation of technology use, open-ended questions, semi-structured questions, and contrast questions regarding the participant's perception of STARBRIGHT World. The researchers presented the emerging themes to the participants during individual closing interviews and in a final focus group to assess if the themes found by the researchers were viewed as accurate by the participants.

QUALITATIVE ANALYSIS

Analysis of data was continuous throughout the case study as data was collected. Two researchers analyzed the audiotapes, transcripts, and field notes. The researchers independently identified emerging recurrent concepts and applied a code to the raw data. The open coding system was used to identify those themes that related to the experience of ESRF, treatment, side effects, coping strategies, STARBRIGHT World technology, and any other recurring themes. Negative cases and conflicting information provided researchers with new interview questions. Results were reported in a case study format with common themes expressed in a corresponding table.

RESULTS

The case study was conducted over a 3-month period involving approximately 350 hours of data collection with individual participants. Themes are summarized in Table 1 and are illustrated in the following case examples using quotes according to the perspective of each participant.

TABLE 1
Identified Themes

End Stage Renal Failure	Coping	STARBRIGHT Technology
<i>Characteristics</i>		
Inability to participate	Active participation	Distraction
School	Following diet	Activities
Strict diet	Taking medicine	Music
Friendships	Attending dialysis	Games
After school activity	Fluid intake	
Wasted Time	Focus of future	Peer/Community
Long hours	Dialysis gives life	Email
Boredom	Attend school	Connect
Tired, weak, sleepy	Employment	Find-a-Friend
Physical Symptoms	Family and Religion	Healthcare Information
Nausea	Grandmother	As needed
Leg cramps	Parents, siblings	Need for Adult Assistance
Weight Loss	Belief in God	
Exhaustion		

Summarized themes displayed in Table 1 represent the experiences of the three children. In line with the goals of the case study, children were asked about their experiences of ESRF, how they cope with the disease and treatment, and how they view STARBRIGHT World technology. Major themes that were present in all three participants' reported experiences were included.

Three major themes emerged when discussing ESRF. The themes expressed by the children seemed to relate more to the hemodialysis treatment than the disease of ESRF itself. The children expressed instances of feeling left out and not being able to participate in activities. Due to the treatment of the disease, these children could not attend school on a regular basis. They had to keep to a strict diet that did not allow them to join in when peers ate favorite foods like pizza and other "junk" food. Friendships were difficult to establish and keep because they did not attend school regularly and they could not participate consistently in after school activities such as sports or extra curricular clubs because of low energy or because of their treatment times.

The children described the wasted time that was spent in treatment. This was articulated by the many hours spent in dialysis, the boredom of being there for so long, and the physical feelings of being tired, weak, and sleepy that continued to plague them long after each treatment. The children described spending much of their day in bed asleep after each dialysis treatment.

In a related theme, the children described additional physical effects of treatment that affected their lives, including nausea and leg cramps that occurred while having treatments as well as the long-term effects of treatment that included weight loss and gain, stretch marks, and stunted growth.

When asked about coping with ESRF and hemodialysis treatment the children said that they actively participate in the management of the disease. They described their ability to help keep themselves alive by following a diet, taking medicine, attending dialysis treatments, and drinking fluids. The children described focusing on their future goals of secondary schooling, employment, having a family someday, and owning a home. This focus on the future seemed to help them endure what they were experiencing in the present. All three children expressed that their families and their religion were their support systems. Friendships were developed with siblings or cousins rather than peers in school, families attended church multiple times each week, and their faith and trust in God helped them to believe that they would live. In one case, the use of religious oil rubbed on the skin by family members was considered part of the treatment of ESRF.

When asked to discuss STARBRIGHT World technology, the children provided information that confirmed previous findings. The children enjoyed the distraction of having activities, music, and games to keep them occupied while undergoing hemodialysis treatments. The children developed friendships through the email, Connect, and Find-a-Friend functions of the technology. Healthcare information was accessed on an as needed basis. For instance, the information was accessed when a treatment change and procedure was impending or when one of the children needed to write a report on a healthcare related topic for school. Finally, these children demonstrated a need for adult assistance in using the STARBRIGHT World technology in the hemodialysis unit. The children struggled with the keyboard due to the hemodialysis line in their arm and they had some difficulty establishing their user information when the technology was introduced. Brief adult assistance remedied these problems.

JOSEPH'S PERSPECTIVE

Joseph expressed the importance of participating in after-school activities such as sports and band practices, because he misses so much of his regular education. He stated, "Seniors have all kinds of stuff. They have like little senior picnics or . . . senior skip days." He would like to participate in these. Joseph described that he has limited friendships at school as a result of ESRF diagnosis, "I try not to talk a lot (at school) because you don't really actually have a lot of friends." He continued to explain that he relies on family for social support, "Only friends I really have are my cousins." When asked, "What do your friends say about your disease?" Joseph responded, "Nothing, most of them don't know. I don't usually want people to know because they think I'm handicapped and I don't like that."

Joseph feels overwhelmed by the time he has to spend in the kidney dialysis unit, "Man, it wastes up time. In here, you don't have a lot to do." He described the treatment as, "Boring." Joseph explained the long hours, ". . . some people run like 2, 3, 4 hours because everybody's body is different."

Joseph was particularly concerned about weight loss and his physical appearance to such an extent that he mentioned it in every interview. He explained that the treatment of ESRF, ". . . makes you lose a lot of weight and it makes you weaker than everybody (anyone) can handle." When prompted to discuss how the treatment made him feel, Joseph replied, "Sometimes you feel weak and sometimes you feel all right. And then if you like going to sleep, you are real sleepy and don't want to get up and then you are weak because you have been asleep for so long."

Joseph knew that he could control his health by actively participating in his treatment. He described taking medicine, avoiding certain foods and attending dialysis. Planning for the future was another way Joseph indicated an internal locus of control. He was a senior in high school and talked about graduating and living on his own, "I'm trying to move out and then once I get my house, a nice little, two bedroom house . . . pay all my bills myself . . . and get all the furniture . . . and see how much money I have left and then I'll see if I have enough to get my own car and pay for the insurance."

Joseph lives with his grandmother and relies on her for emotional support. He referred to church and explained that he attended on Wednesdays and Sundays. He chose to attend a church with a contemporary style of worship and peer support through youth activities. Joseph described his belief system, "I believe in healing . . . I believe anything is possible even if it takes years and years and years. You just have to believe."

Email and the Connect feature of the STARBRIGHT World technology appeared to be the most popular with the kidney dialysis patients. Joseph explained that he liked to "see if anyone wrote me back," referring to the email feature of STARBRIGHT World technology. When asked, "What is the best thing about STARBRIGHT World?" Joseph responded, "Let's see . . . meeting new people." Joseph met a girl in California when visiting a chat room. She was also a kidney dialysis patient and about the same age.

In their conversations, they discussed and shared their experiences of the disease as well as other mutually interesting topics. Joseph said, "Do you get sick sometimes?" Friend: "It's like my head and chest feel hot. I almost passed out last Monday." Joseph: "My head feels like someone is pounding on it." Friend: "Yeah. Then when I'm off (kidney dialysis), I feel like a prune." Joseph: "Me too." The friendship continued through personal emails to each other. Friend: "This is almost too perfect." Joseph: "What do you mean?" Friend: "You have the same disease as me. And perfectly spaced in age. It's weird." The rarity of the disease makes it unusual for children to be able to find true peers.

TALISA'S PERSPECTIVE

Talisa talked about her restriction from activities, school and friendships. She said, "Like going outside to play. I have to stay here for four hours and I don't get to go outside . . . I won't have no-one to play with." Talisa had not been able to attend public school for two semesters and was excited at the prospect of getting to return. "I'll get to have friends again."

Talisa also expressed wasted time due to sleepiness and feeling weak after a treatment ended. "You feel weak after a treatment. You like go to sleep, you

are real sleepy and don't want to get up." Talisa goes home after her treatments and sleeps, which takes up most of the day. This time spent sleeping means these children miss out on additional social opportunities.

Physical symptoms were evident throughout the treatment process. They each experienced nausea and vomiting. Leg cramping was common during dialysis treatment. At one point, Talisa was crying out from pain and Joseph took her by the foot, helping to flex and relax her leg to reduce the pain from cramping. All participants were concerned about weight loss. Talisa had gained and lost so much fluid that her body, particularly her arms, legs and stomach were riddled with stretch marks. She felt self-conscious about this and liked to keep herself covered.

Talisa discussed taking medicine as an active way she could control her own health. When asked, "What can you do to make yourself healthier?" Talisa replied, "By eating the right things and following my fluid restrictions and taking my medicine and taking my binders (potassium)." Talisa expressed an understanding of the need for and benefits of consistently attending dialysis by saying, "I'd rather come here and get better than dying." She knew that participating in dialysis kept her healthy. "It helps your kidneys a lot and it washes your blood and when you get finished getting off, they give it back to you. And they clean your blood . . . and your kidneys . . . and get all the fluid off of you that you have been drinking."

Talisa also evidenced an internal locus of control by keeping a focus on and hope for the future. When asked, "What are your dreams for this year?" Talisa replied, "Getting a good report card." She continued to express a desire for "passing to the sixth grade" and eventually going to high school and the prom.

Strong support systems provided through family and religion were expressed. Talisa's grandparents and aunt moved in with her family and she described relying on her grandmother for emotional support. When prompted to talk about her family, Talisa replied, "I love my family." She talked about her parent's generation of siblings and each of their children. She ended the conversation by discussing a family reunion style Christmas party that was given in honor of her great, great grandfather. She delighted in recounting the details.

Religious beliefs helped Talisa cope with ESRF. When asked, "Do you ever talk to them (family) about kidney disease?" She replied, "Sometimes I say I wish I never been sick and sometimes I ask my mom, Will I die or not? and she just tells me, 'just pray'." In Talisa's life religion played a major role. She described the family practice of rubbing "blessed oil" on her body and praying. They attended church weekly.

Talisa's interaction with STARBRIGHT World technology included looking up food recipes, especially chocolate, as one of her favorite activities. In addition, she liked the music video clips with Christina Aguilera as her favorite entertainer. However, she appeared to enjoy the contests the most. She participated in several contests, winning one and receiving a mouse pad and certificate from STARBRIGHT. She was thrilled and motivated to check her email regularly to see if she had received messages.

BARBARA'S PERSPECTIVE

This participant had been attending public school daily until her hemodialysis treatment began. During the case study, this participant was attending homebound schooling and attempted to attend public school twice a week. Barbara expressed losing touch with friends at school due to an inability to attend school regularly. She stated, "I don't get to go to school." Barbara discussed feelings of exhaustion, she described it by saying, "I get on the machine (kidney dialysis) for three hours and then I go home and rest because the machine makes me tired."

In coping with her illness, Barbara reported that she was not supposed to eat "Ravioli, Spaghetti O's, spaghetti, nothing with red sauce." When probed by the researcher she responded, "Because red sauce has too much salt in it." When asked what she felt was the best thing about kidney dialysis, Barbara replied, "It keeps me alive."

Barbara, too, reported a focus on the future and described wanting to "Grow up and be a fashion designer" or "work in a restaurant because I like to cook." Barbara's family including both parents and her younger brother were supportive and attended her dialysis treatments on a regular basis.

Barbara's favorite interaction with STARBRIGHT World was playing games, especially Cartoon Network. She reported that she watched Cartoon Network television at home and the games seemed to comfort her due to their familiarity.

OTHER OBSERVATIONS

Participants experienced some difficulty in using STARBRIGHT World due to the dialysis treatment and equipment. Three catheter lines were placed in the non-dominate arm and a blood pressure cuff was placed on the arm that participants used to manipulate the mouse and keyboard. Automatic blood pressure measures would intermittently be taken and the participant would be prompted by the nurse to keep their arms straight and still. This hindered their full participation in some of the STARBRIGHT World activities such as art contests or keeping the pace in a chat room. In addition, the children

expressed frustration with the technology when they had trouble finding a screen name initially or other technical problems. Although STARBRIGHT World is designed to be an independently used product, some assistance from an adult was necessary when the children ran into problems.

The participants in this case study did not unanimously show interest in obtaining health information from STARBRIGHT World. Although they were introduced to all features of the technology, participants predominantly used features that provided peer interaction or distraction rather than health information. Only when a novel procedure was necessary did they access the information portions of the technology. At these times, the information and education was helpful in describing what should be expected and explaining why the procedure was necessary.

DISCUSSION

The findings in this case study contribute to the literature by providing children's personal experiences of ESRF and its treatment. These children shared experiences that illustrate the impact of ESRF on their lifestyle and relationships. Many of the experiences reported provide insight into why children with chronic illness have trouble adapting socially in school and experience elevated levels of anxiety (La Greca, 1990).

An important contribution is the documentation of children's ability to cope with ESRF, hemodialysis treatment, and the many physical side effects. These children actively participated in their treatment including attending dialysis, following dietary restrictions, consistently taking medication and monitoring their fluid intake. Consistent with existing social theories of coping and resiliency, the participants' active participation and knowledge of how they could keep themselves healthy helped them maintain an internal locus of control over their illness (Wilson, 1989). In addition, these children shared their determination to focus on the future and keep a positive attitude regarding their future goals and dreams. Finally, the children's reliance on family for social support may indicate a resiliency factor that illustrates how these children are able to adapt when not offered the same social opportunities as other children.

This case study provides qualitative evidence of the benefits of STARBRIGHT World technology as described by the children who use the technology. Participants reported that STARBRIGHT World was helpful in providing distraction when enduring the long, reportedly boring, and uncomfortable treatments. Participants also appreciated the opportunities to make friends and relate to them using the technology. The children were excited

at the opportunity to be involved in the STARBRIGHT World community by participating in activities and games. Finally, while the children were not always interested in using the information portions of the technology, it may be that children use this portion of STARBRIGHT World as the need arises.

Although limited by the case study approach, the thematic findings provide insight into ways of providing further support for these children. Strengths of the case study include the use of established qualitative methods including a conceptual framework, corresponding research questions, prolonged contact with participants, identification and explanation of negative cases, and member checking to affirm reliability of data (Miles & Huberman, 1994; Patton, 1990).

IMPLICATION FOR PRACTICE

Implications for practice include the potential benefits that children diagnosed with ESRF may receive if given the opportunity to use STARBRIGHT World technology. Although over 80 pediatric units across the country have access to STARBRIGHT World, many hemodialysis units do not have the opportunity to share the technology. As evidence is gathered demonstrating the technology's many benefits, it is important to identify ways to increase access. In this case study, the STARBRIGHT World computers were placed on rolling carts to facilitate ease in movement and access for multiple users in different locations of the hospital.

In the future, STARBRIGHT World technology may be available from outside the pediatric unit, perhaps through a login from the Internet. This and other technological developments will assist in expanding the technology's use and help foster continued and enduring friendships when children leave the pediatric unit.

Other pragmatic implications for practice include the possible need for adult assistance for children using STARBRIGHT World technology. Children who have access to STARBRIGHT World technology may benefit from a trained and available staff person or volunteer to facilitate the technology's use. The children in this case study expressed some frustration over initial log-on information and later technical difficulties that may inhibit use of the technology if a knowledgeable adult were not available to assist.

The coping strategies identified by these children offer insight into how educators and related service providers may support children in similar circumstances. Implications for practice include providing education for children diagnosed with ESRF in the care and treatment of their illness. Encouraging children to actively participate in the treatment of their illness and maintenance of health may increase resilience and sense of personal con-

trol. Educators should be aware of the necessary absences from school that these children face and the effects these absences have on their self-esteem, social life, and academics.

Recognizing the important role that family members play in the lives of these children points to another opportunity for educators and related service providers to facilitate children's resiliency by encouraging family support and participation. Collaboration between home and school may make a significant difference in these children's lives by coordinating academic assignments and social activities around the needs of the child. Finally, developing children's focus on future life goals, as the children in this case study describe, may help children cope with the disease.

CONCLUSION

Education and related services for children with physical disabilities necessitate a constant process of reviewing best practices as innovations in education, healthcare, and technology emerge. This case study focused on the emerging need for attention to the psychosocial health of children diagnosed with ESRF as these children increasingly survive to later developmental ages of adolescents and adulthood. Awareness of children's life experiences can assist in understanding their needs. Additionally, this case study contributes further evidence to the growing body of knowledge demonstrating the many applications and benefits of STARBRIGHT World technology.

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